



National Cancer Institute  
Office of Biorepositories and Biospecimen Research  
National Institutes of Health

## **The Ethical Use of Pediatric Biospecimens in Research**

October 24, 2008  
8:30 a.m. – 5:00 p.m.

Neuroscience Conference Center  
6001 Executive Boulevard  
Rockville, Maryland

### **DRAFT AGENDA**

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8:00 a.m. - 8:30 a.m.	<b>Registration and Breakfast</b>
8:30 a.m. - 8:50 a.m.	<b>Welcome</b>  Carolyn C. Compton, M.D., Ph.D. Director, Office of Biorepositories and Biospecimen Research National Cancer Institute, NIH
8:50 a.m. - 9:10 a.m.	<b>Ethical Perspective on the Use of Pediatric Biospecimens in Research</b>  Robert “Skip” Nelson, M.D., Ph.D. Pediatric Ethicist, Office of Pediatric Therapeutics Food and Drug Administration
9:10 a.m. – 9:30 a.m.	<b>Regulatory Perspective on the Use of Pediatric Biospecimens in Research</b>  Lisa Rooney, J.D. Division of Compliance Oversight Office for Human Research Protections
9:30 a.m. – 9:50 a.m.	<b>IRB Perspective on the Use of Pediatric Biospecimens in Research</b>  Mark Schreiner, M.D. Chair, Committees for the Protection of Human Subjects (IRB) The Children's Hospital of Philadelphia
9:50 a.m. – 10:20 a.m.	<b>Panel Discussion</b>  Robert “Skip” Nelson, M.D., Ph.D. Lisa Rooney, J.D. Mark Schreiner, M.D.
10:20 a.m. – 10:40 a.m.	<b>Coffee Break</b>

10:40 a.m. – 11:00 a.m.	<p><b>What Do Research Participants Expect from the Consent Process?</b></p> <p>Carol Weil, J.D. Office for Human Research Protections On detail at: Office of Biorepositories and Biospecimen Research National Cancer Institute, NIH</p>
11:00 p.m. – 11:20 p.m.	<p><b>Practical Perspective on Pediatric Biobanking: The Children’s Oncology Group Tissue Bank</b></p> <p>Jay Bowen, M.S. Biopathology Center Research Institute at Nationwide Children's Hospital</p>
11:20 p.m. - 11:50 p.m.	<p><b>Panel Discussion</b></p> <p>Jay Bowen, M.S. Craig Lustig, Executive Director of the Children’s Cause for Cancer Advocacy Paul McKay, President and Director of the Brain Tumor Action Network Carol Weil, J.D.</p>
11:50 p.m. - 1:00 p.m.	<p><b>Lunch</b></p>
1:00 p.m. – 3:00 p.m.	<p><b>Interactive Discussion: Should Consent Be Sought at Age of Majority from Former Pediatric Biospecimen Donors?</b></p> <p>Moderator: Carol Weil, J.D.</p>
3:00 p.m. – 3:15 p.m.	<p><b>Coffee Break</b></p>
3:15 p.m. – 4:45 p.m.	<p><b>Interactive Discussion: Does Genetic Research Present Additional Considerations for the Use of Pediatric Biospecimens?</b></p> <p>Introduction: Elizabeth Thomson, DNSc, R.N. National Human Genome Research Institute National Institutes of Health</p> <p>Moderator: Nicole Lockhart, Ph.D. Office of Biorepositories and Biospecimen Research National Cancer Institute</p>
4:45 p.m. – 5:00 p.m.	<p><b>Closing Remarks and Adjournment</b></p>